

Special Health Services (SHS)
Family Advisory Council Meeting
January 26, 2019

Attendance:	
Family Advisory Council Members	Abbi Berg, Arica Rezac, Sarah Carlson, Evelyn Klimpel, Joe Liccini, Garrett Schultz
SHS Division Staff	Kim Hruby, Tina Feigitsch, Tammie Johnson, Amy Burke, DeNae Tokach
Welcome and Introductions Kim Hruby	Special Health Services (SHS) Division Director, Kim Hruby, provided a warm welcome and relayed appreciation to the Family Advisory Council for their time and commitment in assisting the division in its work throughout the year. Roundtable introductions were done.
Icebreaker Abbi Berg	Icebreaker activity presented by Abbi Berg – “Question in a bag” <ul style="list-style-type: none"> • A bag with icebreaker questions was passed around the room and each person drew a question. <ul style="list-style-type: none"> ◦ Example: What did you want to be when you grew up?
Announcements All Staff	<u>Upcoming Conferences/Training Opportunities:</u> <ul style="list-style-type: none"> • Disability Awareness Day at the Capital, January 31st, 2019 • Association of Maternal & Child Health Program (AMCHP), March 9-12, 2019 in San Antonio, TX • ND School for the Blind family weekend in Grand Forks, March 22-23, 2019 <ul style="list-style-type: none"> ◦ Email Sarah Carlson if interested in attending • North Dakota Association of Community Providers (NDACP) in Bismarck at the Ramkota, April 23-25, 2019 • Presentation with Dr. Kari Casas on Fragile X Syndrome, Date pending <ul style="list-style-type: none"> ◦ Studies show a link between Fragile X Syndrome and Autism • Amy Burke reported that the NewSTEPS Long-Term Follow-Up workgroup is exploring doing national focus groups with parents whose children have a condition identified through newborn screening - to ensure that all newborn screening programs are asking consistent questions to families and would be able to provide consistent data • A Family Voices Extended Learning call on Newborn Screening, February 7, 8:00 pm Via Conference Call

SHS Programmatic Updates All Staff	<p><u>Update Regarding the List of SHS Medically Eligible Conditions:</u></p> <ul style="list-style-type: none"> • Attention Deficit Hyperactivity Disorder (ADHD) will be an eligible condition starting February 1, 2019 <p><u>Legislation Updates:</u></p> <ul style="list-style-type: none"> • SHS Budget was presented to the House Appropriations Committee • Family Voices emailed testimony supporting Special Health Services
Last Meeting Follow-Up and Approval of Minutes Kim Hruby	<p><u>Review and follow-up items to be addressed from last meeting on September 15, 2018</u></p> <ul style="list-style-type: none"> • All items requested from the council were completed <ul style="list-style-type: none"> ○ The council had requested that SHS provide a list of other councils within the Department of Health, in which family members can get more involved <ul style="list-style-type: none"> ▪ The new Health Equity Office has a new group formed and would like family representation ▪ If interested, please contact Krissie Guerard at kguerard@nd.gov <p><u>Minutes and Recommendation/Review Summary from September 15, 2018</u></p> <ul style="list-style-type: none"> ○ Sarah motioned to accept the minutes. Garrett seconded the motion. Motion carried to accept the meeting minutes as written
Family Story Garrett Schultz	<ul style="list-style-type: none"> • Garrett presented a slide show and gave his family story
Family Advisory Feedback on NBS Long-Term Follow-Up Care Coordination Amy Burke	<p><u>Suggestions for the Newborn Screening Survey</u></p> <ul style="list-style-type: none"> • Sarah suggested including transportation concerns to the list of follow-up questions • She also recommended adding another question on the provider survey to include not only “Is the client receiving Early Intervention services?” but also “Was a referral made to Early Intervention?” • Abbi recommended that during the first year there should be a quarterly call to the family because a year maybe too long to get linked with resources

	<u>Recommended Ways to Engage Families</u> <ul style="list-style-type: none"> • Blogs • Infographics • Twitter • Email out links to families for podcasts, blogs, etc.
Presentation on the ND State Council on Developmental Disabilities	Julie Horntvedt was not able to present due to illness
Legislative Messaging Packets Sarah and Moe	<ul style="list-style-type: none"> • Moe was unable to attend this meeting • Sarah asked that we provide messaging packets sample for the Legislators at Developmental Disability Day • Sarah asked that we have the information to her or Moe as soon as possible <ul style="list-style-type: none"> ○ SHS Fact Sheet ○ Family Voices testimony supporting Special Health Services ○ Family Stories <ul style="list-style-type: none"> ▪ Stella's Story is already available from past but will need to have the Department of Health logo removed ○ Family Advisory Contact Sheet <ul style="list-style-type: none"> ▪ Remove date of birth (just include child's age) ▪ Address ○ 300 copies of SHS brochures to be sent to Sarah
Closing Remarks/Wrap-Up and Reimbursement Kim Hruby	<ul style="list-style-type: none"> • Volunteers were asked for the upcoming Medical Advisory Council Meeting <ul style="list-style-type: none"> ○ Garrett & Joe volunteered to come to Medical Advisory Council in May 2019 • Reimbursement Forms/Adjournment <ul style="list-style-type: none"> ○ Forms were collected, and member information and updates were verified

Upcoming SHS Family Advisory Council Meeting Dates for 2019	<ul style="list-style-type: none"> • May 4, 2019 1:30 p.m. – 4:30 p.m. • September 14, 2019 9:00 a.m. – 12:00 p.m.
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SHS Family Advisory Council Recommendation/Review Summary

Meeting Date	Advice and Follow-Up	Action Taken
January 26, 2019	<ol style="list-style-type: none"> 1. Mail any new members an orientation manual for the SHS Family Advisory Council. 2. Reschedule Julie H. for the next available FAC meeting 3. Membership terms will be reviewed at the next meeting in May. 4. The following should be incorporated into the Newborn Screening follow-up surveys: <ul style="list-style-type: none"> • Questions about transportation issues should be asked • A question should be added for the provider section about whether a referral was made to Early Intervention • Quarterly contacts with the family should replace 	<p>A manual was sent to Arica and extra copies are available for potential new members.</p> <p>Julie H. indicated she would be available to present at the September 2019 meeting. The January meeting minutes also included a copy of the DD Council's Consumer Leadership Development Fund Application for consumers or parents. This allows families to apply for assistance in paying for a training.</p> <p>A celebration of members exiting the council will take place at the May meeting.</p> <p>Immediately following the meeting, Amy Burke contacted MAVEN staff and incorporated all suggestions into the question package for long-term follow-up surveys.</p>

	the annual contacts, at least for the baby's first year.	
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